Deaf-Blind Perspectives

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Syndromes, Behavior, and Educational Intervention

J.P.M. van Dijk
Catherine Nelson

Introduction

In the past decade, clinician interest in syndromes has increased tremendously. Recently Gorlin, Toriello and Cohen (1995) published a book in which 400 hereditary syndromes associated with hearing loss are described and several of the descriptions make reference to the behavior of the individual with a particular syndrome.

The relationship between heredity and behavior was noted in 1872 by Charles Darwin. He wrote

> 'When he lay fast asleep on his back in bed, often raising his right arm slowly in front of his face, up to his forehead and then dropping it with a jerk so that the wrist fell heavily on the bridge of his nose. The trick did not occur every night, but occasionally'

Since the nose of this gentleman became irritated it appeared necessary to remove the buttons of his nightgown. Darwin continues his story as follows.

> 'Many years after his death, his son married a lady who had never heard of the family incident. She, however, observed precisely the same peculiarity in her husband; but his nose, not being particularly prominent, has never suffered from the blow... One of his children, a girl, has inherited the same trick'

(Darwin, 1872, p. 34).

Language expressions such as 'it runs in the family' make reference to the relationship between heredity and behavior. Some researchers and authors have suggested that a person's behavior is solely dependent upon his gene constellation. In reaction to this point of view, behaviorists such as Watson claimed that stimulus-response chains explain human behavior: One of his famous quotes is

> 'Our hereditary structure lies ready to be shaped in a thousand different ways - the same structure - depending on the way in which the child is brought up'

(Watson, 1930)

These points of view lead us to the heart of the discussion of nature (hereditary traits) and nurture (the role of environment and education).

In some hereditary syndromes, nature's role is apparent. A deviant chromosome [15] in Prader-

In This Issue

Willy Syndrome causes enormous appetite in the children with the syndrome that can easily lead to obesity if unchecked. In Turner Syndrome, one X-chromosome in females lacks a specific trait and it is widely reported that persons with the syndrome have great difficulties in spatial orientation (Schaffer, 1962). However, with this syndrome, as well as others including Usher Syndrome, there is wide diversity in its expression. Rubella is a syndrome not caused by heredity, but rather is acquired in early pregnancy. The extent to which Congenital Rubella Syndrome (CRS) *predicts* a persons behavior, and intellectual and emotional development is largely dependent upon which organs are damaged, and the extent and type of the damage.

It is very important that special educators and others, including parents, understand the influence of certain syndromes on the well being of the individual and his/her family. Cooperation with a geneticist or pediatrician is vital. Bringing typical physical appearance and/or abnormal behavioral patterns to the attention of these professionals may provide crucial leads to the discovery of more about the etiology of the individual. A recent study in the Netherlands (Van Berkum & Haverman, 1995) showed that in a survey of a residential setting for persons with severe intellectual disabilities, 50% of the etiologies were unknown. However, in settings with a strong multidisciplinary focus, the category 'etiology unknown' was significantly less frequently used. The importance to parents of knowing more about the cause of their child's disability should not be underestimated particularly as they make plans to have additional children. Some genetic disorders can be improved through medical interventions that may have a lifelong affect on a person's physical and psychological condition. Recent research has shown that carriers of certain syndromes, while not appearing to actually have the syndrome themselves, may actually have some effects. An example of this is the inborn metabolic disorder called homocystenuria. Without proper vitamin treatment a person who suffers from this disease may deteriorate mentally and physically. Carriers of

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this recessive disease are vulnerable to acquired heart disease that can be prevented by taking a high dosage of Vitamin B6. It is also reported that in another recessive genetic disease, Usher Syndrome, a slight hearing loss might develop in carriers although this finding is not universal (Van Aarem, 1995). Recently we have observed that in non-affected children of a family with members with Usher Syndrome, problems of signal noise ratio were present that made classroom functioning difficult. Since the field of behavioral genetics is so new, it is difficult to say to determine the extent to which certain hereditary diseases explain the behavior and development of affected persons or carriers. However, when interviewing the parents one should pay attention to the presence of [minor] abnormalities in other family members.

There are a number of genetic diseases that involve physical and mental deterioration. Metabolic disorders such as Zellweger and Refsum are notorious for causing such deterioration. Other syndromes have effects that are less noticeable. One example is Stickler Syndrome. A child with this syndrome may function well in school despite a hearing loss, but gradually learning problems arise as visual impairments together with problems with the joints slowly develop.

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A syndrome prevalent in the population of persons who are deaf-blind is CHARGE Association. The complexity of the association has increased awareness of the importance of multidisciplinary collaboration. Among the traits of CHARGE Association is hypogenetalism. When male / female hormones are given to stimulate genital development, behavior such as hypersexuality may result. It goes without saying that all consequences should be considered before medications of this type are prescribed.

The relationship between syndromes, education, developmental psychology and psychiatry has had little study. In clinical, medical descriptions, the effects of disease on behavior and learning is rarely mentioned. The relationship between disease and behavior is not an easy study due to variability of disease expression and the role the environment plays.

Description of three Syndromes

Congenital Rubella Syndrome [CRS]

Congenital Rubella Syndrome is not a genetic syndrome but rather is caused by a virus. In 1941, the Australian ophthalmologist, Sir Norman Gregg, discovered the relationship between Rubella and Congenital Cataracts. He also reported that the babies he investigated had low birth weight and were very difficult to feed (failure to thrive). A few years later, another Australian medical group reported that Rubella infection in pregnancy could lead to partial destruction of the cochlea which caused [partially] deafness. Six years after the discovery by Gregg, the medical journal, 'The Lancet' reported the Australian findings with some hesitancy. In the early and mid sixties, the western world was hit by an epidemic of Rubella that caused almost 35,000 children to be born with one or more sensory disabilities. In 1967, an effective vaccine was developed in the U.S.A. (Parkman, Weller & Neva, 1967). However, it was a number of years before active immunization could be launched. It seems that the most effective policy is to eliminate the disease by vaccinating both male and female children at young age. However, while not common knowledge, there is a small percentage of women who do not develop an-

tibodies against Rubella and these females remain unprotected. Under supervision of the World Health Organization (WHO), immunization programs are carried out in emerging countries. In some countries with very large populations, the results of immunization programs have been unimpressive thus far. It is reported that in schools for the deaf in India, 40% of the students are deaf/hard of hearing due to Rubella infection of the mother during pregnancy. In some of the eastern European countries, the Rubella problem is still very prominent (e.g., Poland and Russia). It is apparent in discussions with professionals in the area of rehabilitation in these countries, that there is still a lack of knowledge regarding the effects of this disease on the behavior and learning of individuals.

The outbreak of the Rubella epidemic in 1964–1965 provided the impetus for the development of programs for children who are deaf-blind in the U.S.A.. A number of important studies were published which focused on the child with multiple disabilities caused by CRS. Because of the emphasis on the group of children with multiple disabilities, little attention was given to the Rubella child with a single disability (e.g., hearing loss/visual loss). It should be noted, however, that Rubella is a late onset disease. This means that later in life, especially during the period of adolescence, medical problems may arise (e.g., diabetes mellitus and glaucoma) that may have considerable effects on the course of life. There is a general agreement that these problems are most manifest in the group of persons with multiple disabilities.

An interesting point in the discussion of syndromes and behavior is the relationship between CRS and autism. In her early publication, Stella Chess confirmed this relationship and subsequently, many publications about the etiology of autism mention Rubella (Siegel et al., 1986; Prior, 1987). In his publication in 1982, Van Dijk reported on 81 Australian children with Congenital Rubella Syndrome and questioned this relationship. In reference to stereotypic behavior that is often observed in children with CRS, he postulated that this symptom must not be seen as a symptom of autism but rather as a symptom of sensory deprivation. When Van Dijk reassessed his sample 15 years later, he discovered that in many subjects who had exhibited stereotypic behavior at a young age, the phenomena had disappeared completely. In his follow-up research, only a small group met the criteria for autism of DSM-III (Diagnostic and Statistics Manual of Mental Disorders Vol. 3). Similar findings are reported by Gilberg (1982). In the follow-up studies of Chess and Van Dijk, the role played by communication in the regulation of behavior is striking. It is generally noted that persons infected by Rubella have difficulty in adapting to new situations. Unexpected events cause considerable stress in these persons that may lead to catastrophic reactions. These may take the form of aggressive outbursts in which the aggression may be directed to the person's own body leading to self injurious behavior (SIB). There is question as to the degree to which this behavioral 'trait' is typical for a person with CRS and related to the vulnerable neurological system of these persons. Despite uncertainty as to the cause of the behaviors, it would appear important that people in the environment take appropriate measures to prevent their occurrence. Providing the individuals with an appropriate means of communication (e.g., sign language) may prevent many such behaviors. However, in some instances, sign language because of its motor complexity, is not the most preferred mode of communication. It had been shown (Van Dijk et al., 1991) that

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limb coordination can be very difficult for individuals with CRS. To compensate for this difficulty, many individuals have developed strong visual skills. Written forms of communication (e.g., pictograms, BLISS symbols and writing) are more effective communication tools than is sign language. Objects of reference, calendar boxes and picture books can be effective tools for expressive communication for children with greater communication difficulties (see detailed description in Van Dijk, Janssen & Nelson, 1993).

In studying the early development of children who are deaf-blind and particularly those with Congenital Rubella Syndrome, it is apparent how very difficult the early period of life is for both the children and their care givers. This, combined with a rather fragile neurological system, may predict the undesirable behavior patterns of later life. The extent to which this prediction becomes reality is very much dependent upon protective factors from the environment. For these children, adolescents and adults, protective factors are: ordering of daily life activities, predictability, and prevention of unexpected, overwhelming life events. It goes without saying that these requirements cannot always be met. In extreme instances, supportive medication may be necessary to help individuals cope with stressful events.

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Usher Syndrome

Mention was made earlier of the heterogeneity of certain syndromes. Usher Syndrome is one in which this is especially true. The Scottish ophthalmologist, Charles Usher, first described this syndrome. In 1935, he lectured on the prevalence of Retinitis Pigmentosa (RP) in a sample of individuals with severe hearing loss. In 1922, Bell noted the heterogeneity of this syndrome, and in 1977, Davenport made a distinction between different types of Usher Syndromes (Davenport & Omenn, 1977). In the last few years, gene localization has clarified the different types (Van Aarem, 1996). Usher type I (profound sensory neuro deafness and decrease in field of vision before puberty) is located on chromosome 11q. Type II (partial deafness and decrease of field of vision after puberty) is located on chromosome 1q. The rather rare type III in which there is progressive hearing loss and progressive loss of field of vision due to RP is located on chromosome 3q. Further gene localization research in relationship to Usher I and Usher II has been conducted by Radboud Hospital (Nijmegen the Netherlands) in cooperation with Boys Town Omaha (Nebraska). It is still unclear whether different gene localization's are responsible for differences in the progression of the disease or even influence the behavior of an individual with the syndrome. In respect to the latter, there has long been discussion about the existence of a fourth form of Usher. Hallgren (1959) reported psychiatric problems, severe stress phenomena and psychosis in a group of individuals with Usher. It is questionable, however, whether this behavior pattern has a hereditary base associated with another type of Usher, or is symptomatic of so-called Post-Traumatic Stress Disorder. This may occur when a person with Usher loses an important person in his / her environment or experiences other traumas such as the loss of employment or becoming unable to care for one's family. Our clinical experience with a large group of individuals with Usher type I is that a 'stress disorder', if it lasts only a short period of time, seldom leads to psychosis if adequate support is provided. Research has been carried out on

the psychological resilience of persons with Usher I. The first author assessed a group of adolescents with a Dutch revision of the American California Child Q-set. People very familiar with the subject's functioning were asked to complete a questionnaire concerning the subject's ego-resilience, ego-strength, social competence, ego-control and self-esteem. The study shows that 88% of the group (N=16) scored high to very high on the profile of ego-resilience in comparison to the deaf children in the norm group. In regards to pro-social competence, it was shown that a significant difference existed when the scores of the Usher group were compared with those of the peers in the norm group. A lack of assertiveness was quite striking. In 89% of the cases of Usher I, there was a high to very high score on the self esteem scale. Because of sample size, caution should be used in the interpretations of the findings. Recently the original sample was reassessed. Four years after the initial research, the same behavioral profile was still found and was also present in 9 additional cases (Van Dijk & Van Erp, in preparation). Our clinical experiences confirm these findings of favorable social emotional profiles in individuals with Usher 1. After having assessed about 100 such individuals (about 1/3 of all individuals with Usher Syndrome in the Netherlands), we have found that they readily accept advice and return regularly to the clinic for counseling. It would be interesting to know whether these striking behavior patterns occur only among the Dutch group or are also found in other samples. One might speculate as to whether this 'emotional strength' is a natural (genetic?) reaction of a human being when experiences such as severe sensory losses occur.

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CHARGE Association

Previously known as CHARGE Syndrome, the term Association was adopted because of the extensive variety of symptoms found. CHARGE association is one of the 25 most prevalent genetic syndromes of individuals with multiple disabilities. It was described for the first time in 1979. Several organs are involved, most of which develop in the 3rd - 7th week of pregnancy. CHARGE is an acronym for its most striking symptoms.

The C is for coloboma. This means that the iris and / or retina is not completely closed leaving an open hole that looks like a keyhole. When the iris is not closed, the light hits the eye in such a direct manner that in clear weather conditions the child is very uncomfortable. Some young children with this condition refuse to go outside when it is sunny. When the retina is not completely closed, the lower part of the retina often does not function. This segment of the retina receives stimuli coming from above. A child with this condition might be afraid of moving targets (e.g. a ball which enters his field of vision from above). The child may only become aware of a person coming down from the stairs when he or she is very near. Fragile health and motor delays common in children with CHARGE may result in the child spending much of his early life lying on his back. When lying down, the lower segment of the retina is normally used, but since this is often where the coloboma is, the child may spend many months in a position where he is severely visually deprived. When the child is put in an upright position and objects are presented from underneath, the exploratory behaviors may dramatically improve. In cases where a coloboma is present, it is likely that the retina is rather weak and it may detach.

This process can develop so gradually that it goes on unnoticed. It is possible that a child with CHARGE Association may gradually become blind without the occurrence of any trauma. Educators should be made aware of the vulnerability of the eyes in children with CHARGE. Observed changes should be reported immediately to an ophthalmologist.

The H of the acronym is for heart abnormalities which are reported in 50% of cases. The A is for atresia of the choanae. The R for physical, and in some cases mental, retardation. The majority of individuals with this Association do appear to have severe cognitive disabilities, however there are cases of individuals with normal intellectual development (Harvey et al. 1990). The letter G represents underdevelopment of the genitalia (both male and female) which is reported in 40% of cases. It is assumed that genital hypoplasia is due to an insufficiency of the hormonal system, therefore some children with the Association exhibit no signs of puberty. As previously mentioned, hormonal treatment should only proceed with great caution. The E is for anything having to do with ears. In 85% cases, hearing loss of varying degrees is reported. When there is an opening of the palate in addition to deafness, speech possibilities are limited. The use of alternative and augmentative communication devises should be considered.

. . .parents also need to be supported as they deal with a child who may exhibit stereotypic or compulsive behaviors.

CHARGE Association is not limited to the 6 symptoms mentioned here. Recently a child was assessed with CHARGE who refused to ride her bike. Further investigation indicated a dysfunction of the vestibular system. She had been so traumatized by attempts to teach her to ride the bike that she would not even go near it, but she immediately went to a tricycle that requires little balance as she knew that she could move independently on it.

Discussion

This article has only touched upon the intriguing question of to what extent certain syndromes are related to an individual's behavior. Behavioral genetics tells us a great deal about the role of the genes and the environment. Studies of twins are very important to the science of behavioral genetics as identical twins have the same genes, yet the environment they share is partially the same (e.g. the same parents) but also different, for example, different friends (Plomin, DeFries & McClearn, 1990). In studies of psychiatric diseases such as schizophrenia and psychoses, it is apparent that whether or not a disease that is 'in the genes' manifests itself is dependent upon the non-shared environment. Important environmental factors mentioned are stress, early deprivation, limited, or poor social contact with parents, and divorce (Plomin & Daniels, 1987). In behavioral genetics, emphasis is placed on supporting the factors that may prevent a person with a certain predisposition from developing difficulties. Family relationships, especially mutual support of the parents (see also Van Dijk, 1991), adequate counseling, and a thorough diagnosis are such supports.

It is our opinion that findings of the behavioral genetics also apply to children who are deaf-blind. We would like to stress the importance of the manner in which people in the environment deal with a child with CRS, a child with Usher Syndrome, or a child with CHARGE Association. For a child with Congenital Rubella Syndrome, parents and other caregivers need to support the child through the organization of a quiet and understandable world. At the same time, parents also need to be supported as they deal with a child who may exhibit stereotypic or compulsive behaviors.

Good respite care by trained providers such as intervenors can provide such support.

Parents and siblings of a child with Usher Syndrome may go through an extended period of mourning which can prevent the child from developing to his / her fullest potential. The family may avoid the whole topic of the child's eyes. Teachers or employers may not even be told about the child's condition. Counseling which takes into account the family system should be considered. The goal is to create a climate in which the child with Usher Syndrome can make important decisions in his / her life.

There are many obstacles that the family of the child with CHARGE Association must deal with. In the beginning, medical issues may be overwhelming and extremely stressful. Parents will need good information on how the child should be fed and how hearing aids and glasses should be worn and used as they learn that they can help their child learn and develop in positive ways.

The field of genetics a rapidly growing one. There are more than 400 syndromes described in which deafness plays a role (Gorlin et al., 1995). In about 20% of these syndromes, both auditory and ocular involvement are reported. It is our sincere belief that only through the various disciplines working together as a team can adequate care for the child and his / her family be provided. Decisions by the team should always include the parents and if possible, the individual with the disability. The team must formulate recommendations that carefully consider the role of the environment. It is our conviction that negative outcomes can be prevented despite the presence of many symptoms. We have adapted a motto that the more one knows about 'genetics' the more one becomes aware of the importance of the role of the environment.

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Words From the Past Managing Editor

Bruce Bul[1]

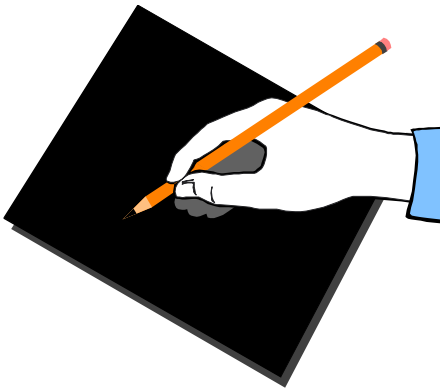
Given a point-in-time perspective, things seem static. Over time however, it is apparent that everything is in a state of change; our jobs, our world, and ourselves. Little did I know that the previous issue of *Deaf-Blind Perspectives* would be my last. I have recently taken an exciting position within the Oregon Department of Education and wanted to share a few parting thoughts.

Deaf-Blind Perspectives too is poised for change. In the last issue we started a Letters to the Editor section, an important forum for people to share, discuss, and challenge. Keep the letters coming! Keep the publication alive with dialogue about the issues.

During my tenure at *Deaf-Blind Perspectives* we would always seek quality manuscripts. The focus of each issue changed based on the contents. The better the content to choose from, the better the publication. Let me encourage you to submit manuscripts of a personal or professional nature. If you'd like to see change in some aspect of our field, use *Deaf-Blind Perspectives*.

About change, my father used to say, "A change doesn't always bring improvement. But you can't improve without change." Let's continue to work to improve this field.

We will miss you Bruce, and wish you the very best.—ED.



Letters to the Editor

Dear Editor,

Over the course of the last few years a number of agencies and associations in the field of deafblindness have dropped the hyphen from the disability category "deaf-blind." It is our opinion and suggestion that *Deaf-Blind Perspectives*, a distinguished publication both nationally and internationally in this field, adopt this current terminology.

There are good reasons to consider this change. First, deafblindness presents challenges that are not simply the compilation of deafness and blindness. In 1991 Salvatore Lagati wrote to 30 agencies around the globe stating:

> I think that people that are deaf and blind should be called deafblind, and not deaf-blind. For the simple reason that deafblindness is a condition presenting other difficulties than those caused by deafness and blindness. So in my mind the word deaf-blind is not correct, because it could be interpreted as a condition that sums up just the difficulties of deafness and blindness.

Second, many, if not most, countries now refer to the disability as a single word without the hyphen. Moreover, increasingly agencies within our own country are changing to this terminology (e.g., Hilton / Perkins).

Please consider using the term "deafblind" both in the title of your publication and throughout your publication. *Deaf-Blind Perspectives* serves as an important medium through which professionals, families, caregivers, and people who are deafblind access state-of-the-art information relative to our unique field, and we encourage you to promote this change to better support a more accurate understanding of deafblindness.

Sincerely,

Bruce Bull
Special Education Child Count Specialist
Oregon Department of Education

Bud Fredericks
Professor Emeritus
Teaching Research
Western Oregon State College

Jay Gense
Coordinator
Oregon Project for Deafblind Services
Oregon Department of Education

Steve Johnson
Associate Superintendent
Office of Special Education
Oregon Department of Education

Jane Mulholland
Assistant Superintendent for Special Schools, Regional Programs and Early Intervention/Early Childhood Education
Oregon Department of Education

Deaf-Blind Perspectives, recognizes the diversity in opinion regarding this issue and does not wish to make changes hastily. We therefore invite you to comment with Letters to the Editor.

To assist us in making an informed decision about any modification of the term "deaf-blind," *Deaf-Blind Perspectives* particularly invites the views of people who are deaf-blind, their families, and the professionals who serve them.

We will attempt to print a representative cross-section of your views in subsequent issues. —ED.

Want to share your opinion? Take a few minutes to write a Letter to the Editor. Please keep letters to 250 words or less.

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